

# **What Matters Most: A Patient Perspective on Post-Treatment Surveillance**

Janet Freeman-Daily, MS, Eng  
<http://grayconnections.net>  
[@JFreemanDaily](#)

# Disclosure: I'm a cancer patient on a targeted therapy

photo credit:  
LUNGeivity, 2015

## National Cancer Survivors Day



# Metastatic Patients Are Living Longer



Lung cancer  
patients  
10+ years after  
diagnosis

photo credit:  
LUNGeVity, 2016

# Meaningful Surveillance Measures What Matters to Patients

## Values

a patient's concerns, expectations, and choices  
regarding health care, based on a full and accurate  
understanding of care options

--Institute of Medicine

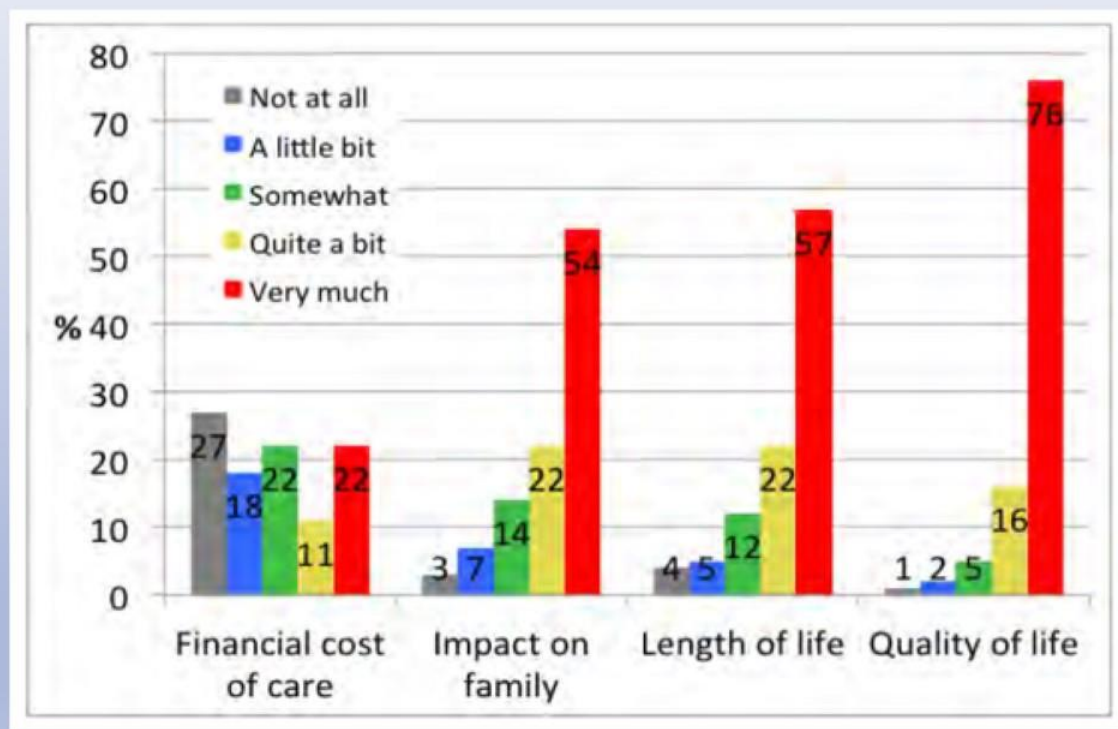
Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. 2013

Meaningful surveillance implies intervention

# What Matters Most to Patients?

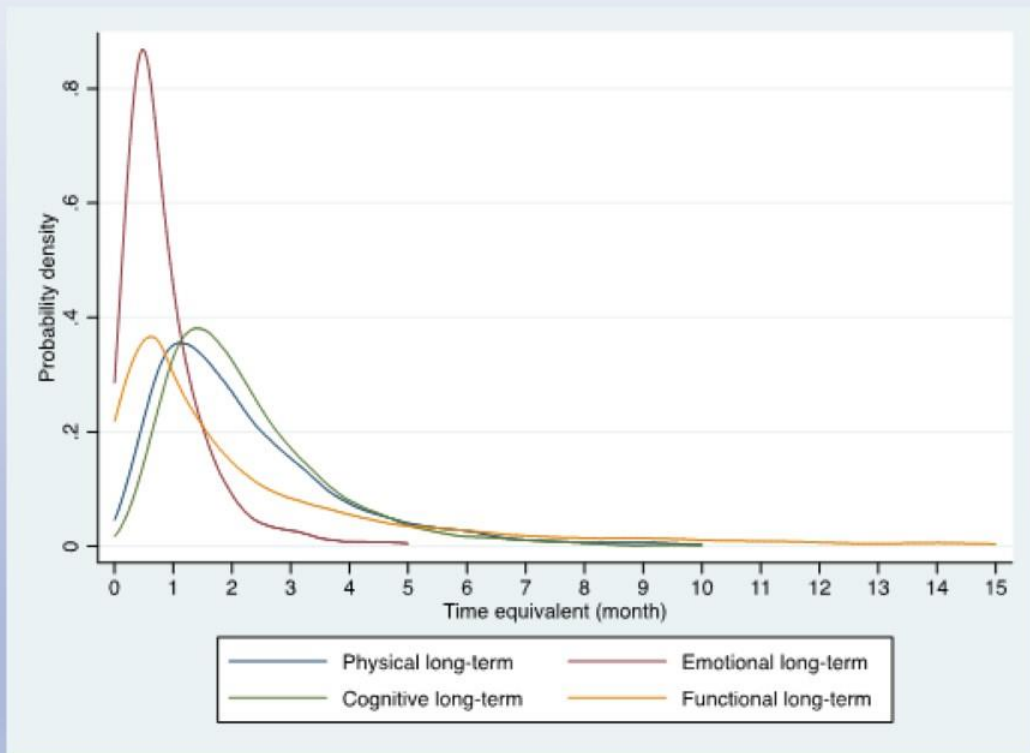


# Patient Priorities in Treatment Decisions



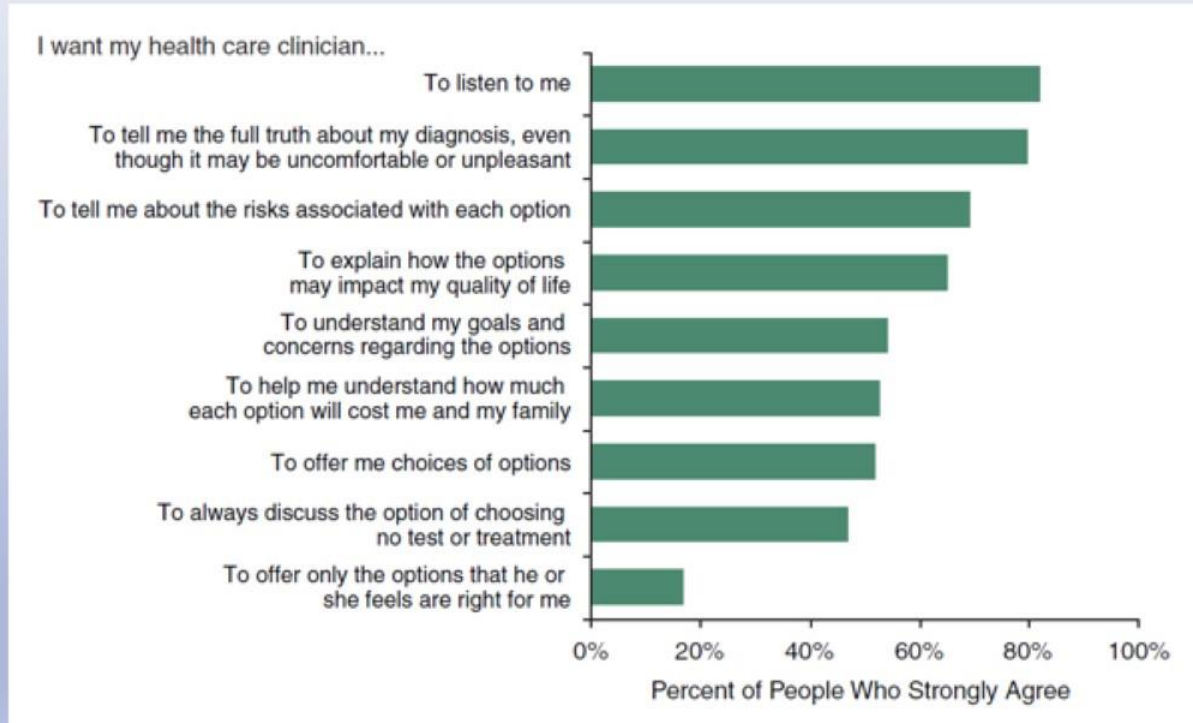
Buzaglo JS, Miller MF, Longacre ML. (2016) Cancer Patients' Priorities When Considering a Treatment Decision. Poster presentation at 8th Biennial Cancer Survivorship Research Conference.

# Patients Concerns About Side Effects



Bridges JFP, Jannsen EM. Project Transform: Incorporating the patient experience into lung cancer treatment, research, and policy, Presentation at LUNgevity National HOPE Summit 2017.

# Patients Value Communication & Truth



Institute of Medicine. (2013). Delivering high-quality cancer care: Charting a new course for a system in crisis. National Academy of Sciences.



# Shared Decision Making: AHRQ SHARE

## 5 Essential Steps of Shared Decision Making



<https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html>

# Goals of Care Discussions Add Value

- For patients facing serious and life-threatening illness, early GoC discussions are associated with improved patient outcomes
- Did not increase pt anxiety, depression, and/or hopelessness



Bernacki RE, Block SD, for the American College of Physicians High Value Care Task Force. Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices. *JAMA Intern Med.* 2014;174(12):1994-2003. doi:10.1001/jamainternmed.2014.5271

# Survivorship Care Plans Need Work

SCP is great idea! Gives patients a summary of treatment, anticipated late effects, recommended screenings

*BUT...*

- Inconsistently developed and delivered
- Do not reflect progression to later stages
- Not provided to stage IV patients
- Who is responsible for long-term follow-up care and surveillance—oncologist? PCP?

# **Innovative Patient-Centered Surveillance Technologies**

# Principles of Patient-Centered Measurement



American Institutes for Research, Principles for Making Health Care Measurement Patient-Centered, 2017.  
[https://aircpce.org/sites/default/files/PCM%20Principles\\_April182017\\_FINAL.pdf](https://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf)



# Myths of Patient-Reported Outcomes

- **MYTH:** PROs are by definition patient-centered
- **MYTH:** If patients are reporting on an outcome, it matters to them
- **MYTH:** If a PROM is published, it is automatically validated for any use case

Cynthia Grossman, Milliken Institute, *Patient Reported Outcomes: Design with the End in Mind*, Jan-2018.

# How Can We Measure Physical Function?

- Physical Function (PF) is a **clinical outcome**, an outcome that describes or reflects how a patient feels, functions or survives:
- Types of COA to measure PF:
  - **Clinician-reported outcome (ClinRo)**: e.g. Karnofsky and ECOG Performance Status
  - **Patient-reported outcome (PRO)**: e.g. EORTC QLQC30 PF and PROMIS® PF
  - **Observer-reported outcome (ObsRo)**: e.g. Parent observing infant's activity
  - **Performance outcome (Perf-O)**: e.g. 6-minute walk test
- Wearable devices/ Biosensors: Can be considered a COA depending on context of use. The science is under development.

BEST (Biomarkers, EndpointS, and other Tools) Glossary: <https://www.ncbi.nlm.nih.gov/books/NBK338448/>

Paul Kluetz, FDA, *Measuring Symptoms and Function: Perspectives from the Oncology Center of Excellence*.  
Presentation in FasterCures Webinar "[Patient-Centered Measurement: How Close Are We?](#)", 22-Mar-2018.

# What Else Might We Measure?

- Symptoms
- Cognitive impacts (memory, attention, word finding)
- Morbidity
- Supportive care medications
- Hospitalizations and emergency room visits
- Medical procedures
- Patient preferences

# Connected Health Tools for Surveillance

- Patient registries
- Surveys of online cancer patient-caregiver communities
- Partnerships with disease-focused advocacy groups
- Partnerships with oncogene-driven cancer communities



# Surveillance Ideas from a Patient Perspective



# Detect Progression/Recurrence

- Detect cancer early, accurately, affordably, easily
- Identify best surveillance protocol for indolent vs aggressive cancers (surveillance or screening?)
- Assess survival *and* QoL outcomes for different cancers, treatment protocols, and detection technologies (liquid biopsy, tumor marker, radiology, PROs)

# Impact of Treatment on Quality of Life

- Impact of various treatments on long-term cognitive effects (especially for drugs that cross blood-brain barrier)
- Type, severity, and time of onset of late effects after immunotherapy
- Impact of Survivorship Care Plan quality and implementation on QoL and detection of second cancer

# Effective Communication Strategies

- Assess communication strategies
  - Goals of care discussions
  - Shared decision making
  - Patient decision aids
- Possible outcome measurements
  - Physical (e.g., ability to function, pain level)
  - Emotional (e.g., depression, enjoyment of life, satisfaction with care)
  - Use of healthcare resources (ER visits, palliative care)
  - Treatments and medications
  - Survival
  - Cost of care to patient & payers